
“What Rights?” The Construction of Political Claims to American Health Care Entitlements

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Despite a growing health care crisis, Americans remain reluctant to treat “health security” as a right or entitlement of citizenship. This article examines the effects of unmet health care needs on the beliefs that individuals hold about family, market, and state responsibility for health security. Drawing on a study of individuals caring for family members with chronic diseases, I find that when imagining solutions to unmet long-term care needs, individuals evaluate a range of alternative social arrangements, but they select the model that is most consistent with previously existing beliefs about family, market, and state responsibility for care provision. This process of discursive assimilation, of integrating new needs for public provision with more familiar ways of thinking about social welfare, produces claims for entitlements that challenge existing social arrangements but do so within a welfare state framework that conceives of only a minimal role for the state in safeguarding social welfare.

In 1993, President Bill Clinton gave a televised address to the nation in which he called on Congress to fix the American health care system by “giving every American *health security* – health care that’s always there, health care that can never be taken away” (from President Clinton’s prepared speech text, as reprinted in Eckholm 1993:301–14; emphasis added). Drawing on the rhetoric and imagery of the popular Social Security program, President Clinton sought to cast health care as an earned entitlement, a permanent commitment by the state to ensure that all Americans have access to adequate health care. The idea that health care provision could be sold to the American public as an entitlement akin to Social Security or Medicare rested on a key assumption about the relationship between social risk and American support for an interventionist

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state: some threats to well-being—such as unemployment, injury, disability, and old age¹—are a widespread and unavoidable feature of a modern industrial society, potentially devastating the lives of individuals who bear the costs of such events on their own. Conventional wisdom about the welfare state holds that the state has both the capacity and responsibility to mitigate these risks by spreading their costs across the broad population (Hacker 2006). President Clinton's attempt to reallocate the risks of market-based health care by expanding the state's role was, in this regard, consistent with the historical rationales for previous entitlement programs. The popular success of Social Security and Medicare attested to the belief that the surest way of protecting certain social welfare needs from the vagaries of the market and popular politics is to characterize them as rights or entitlements of citizenship (Fraser 1989).

But as President Clinton's health security plan subsequently unraveled, it became clear that the American public was in fact deeply ambivalent about bestowing "entitlement" status to health care. On the one hand, most Americans supported—indeed continue to support—increased federal regulation of and spending on health care (Kull 2000:30–32). On the other hand, Americans maintained serious doubts about an expanded state role in health care provision (Jacobs 1993). The reluctance of the American public to endorse the idea of "health security" in the face of well-documented—and growing—unmet health care needs suggests that the relationship between social risks and expectations for social welfare entitlements may be more complex than conventional accounts presume.

We know, of course, that not all social needs have received entitlement status in the American welfare state. Entitlements to state provision in the United States have historically been designed to ameliorate the economic insecurities associated with market participation—originally, to protect male breadwinners from risks such as unemployment or injury that could jeopardize their ability to support themselves and their families (Fraser & Gordon 1992). By contrast, relationships involving care or dependency have historically been treated as the prerogative of families rather than the state; the state initially intervened in these cases only to assist families without a male breadwinner—widows, single mothers, and orphans (Gordon 1994; Fraser 1989). While changing gender norms and patterns of labor force participation have rendered the traditional breadwinner model of social provision obsolete, the cultural assumptions underlying what kinds of social welfare claims

¹ This definition of social risk as a threat to social welfare is somewhat different from the understanding of risk commonly found in the criminal justice literature, which tends to emphasize risk behaviors, such as teen pregnancy, drug use, school failure, violence, etc. (Schehr 2005).

rise to the level of “rights” or “entitlements” have nevertheless persisted. Claims involving the duties and obligations of care—including care for young children, the sick, and the elderly—are rarely advanced in this country by relying on the discourse of rights (Gilliom 2001; Gordon 1994).

While these historical legacies do not themselves explain American ambivalence toward health care entitlements, they point to the important role of cultural norms and beliefs in mediating between unmet social welfare needs and expectations for new social policy arrangements. To understand why Americans are so reluctant to turn to the state as a solution to the health care crisis, we need to first understand the effects of unmet health care needs on the constellation of principles, norms, and beliefs about family, market, and state that shape how individuals choose to resolve social welfare problems in their everyday lives—what I refer to here as *political consciousness*.² Long-standing and deeply held beliefs about responsibility for social welfare do not easily give way in the face of stresses on family or work life but instead play an important role in shaping how individuals conceptualize solutions to their social welfare dilemmas. In this article, I seek to more closely examine how unmet health care needs change beliefs about the interface between family, market, and state, and under what conditions they become the basis for political claims for alternative social arrangements.

The analysis of political claimsmaking (or grievance construction) that follows departs from two literatures that have long examined the shifts in political consciousness that are necessary for individuals to challenge existing social conditions: the social movement framing literature and the sociolegal literature on disputing and legal mobilization. Both literatures are primarily concerned with understanding the conditions in which individuals will pursue—or “claim”—remedies for their perceived problems or injuries. Here I shift the analytical focus away from the mobilization of existing remedies, to instead consider the *construction* of remedies as a key transformative stage in the development of political consciousness. The process of imagining alternative social arrangements for new or newly perceived social welfare problems involves the evaluation of a range of culturally available models (Sewell 1992; Swidler 1986). I argue that in choosing from among these alternatives, individuals turn to those social arrangements that are consistent with more familiar ways of thinking and talking about social welfare (see also Polletta 2000; Primus 1999). In other words, for individuals to accept an expanded state role in health care, they

² This conceptualization is based loosely on Morris’s definition of political consciousness as comprising “those cultural beliefs and ideological expressions that are utilized for the realization and maintenance of group interests” (1992:362–3).

require a model of state intervention that does not substitute the state for family or market responsibility for health care—as the notion of “health security” implies—but that integrates the need for state assistance into a belief system that privileges family or market responsibility for health care. Understanding “claiming” as the construction—rather than the pursuit—of remedies by grievants promises to not only explain why Americans are reluctant to endorse “health security” as a solution to the unfolding health care crisis, but also to illuminate what forms of public provision might better resonate with the American public as legitimate or appropriate means of ameliorating the social risks posed by existing structures of health care provision.

To elaborate the process by which individuals construct solutions to problems involving health care provision, this article draws on observational, focus group, and interview data from a study of 176 unpaid family caregivers—specifically, individuals caring for adult family members diagnosed with dementia, cancer, or similar chronic diseases. The crisis in American long-term care provision offers a particularly dramatic example of a case involving sharply increasing rates of unmet health care needs and a deeply ambivalent public regarding state intervention. Care provision for society’s most vulnerable has historically been understood to be a family responsibility—and the responsibility of women in particular (Harrington 2000).³ But over the course of the last century, increased longevity and changes in health care provision have dramatically changed the nature of long-term care provision. Today, more families are shouldering the responsibilities of caring for older—and sicker—people than at any time in our nation’s history (Abel 1991; Stevens 1989; Glazer 1988; Koren 1986). Meanwhile, the increased participation of women in the paid labor force and changes in household structure have substantially reduced the primary pool for unpaid family caregivers at a time when the costs of purchasing caregiving services—i.e., in-home supportive services, adult day care, or nursing home care—have escalated sharply (Harrington 2000; Garey et al. 2002).

Despite the well-documented negative effects of contemporary care dilemmas on economic security,⁴ gender equity,⁵ class

³ Even today, women make up approximately 75 percent of all unpaid family caregivers (Brody 2004).

⁴ Caregivers must cope not only with the financial expenses of caregiving, but working caregivers (who now constitute a majority of all caregivers) typically face additional stresses—and costs—relating to missed work and lost job and career opportunities (England & Folbre 1999; U.S. Department of Health & Human Services 1998).

⁵ See Glenn (2000) and Fraser (1997). If the emotional and physical responsibilities of care provision fall disproportionately on women, so too do the economic costs (Wabakayashi & Donato 2005; M. Meyer 1994).

equity,⁶ and the physical and mental health of family care providers,⁷ few market- or state-based policies exist to assist families with the costs or provision of long-term care.⁸ Health insurance policies generally do not cover long-term care supportive services at all, and long-term care insurance has proven to be an expensive, unreliable, and hence substantially underutilized market (M. Meyer 2005). Medicare provides acute care coverage for most of the nation's elderly but very little assistance for patients with chronic illnesses,⁹ and Medicaid provides long-term care assistance only for the very poor. With few market alternatives and little public assistance, then, family caregivers for chronically ill adults represent an ideal group for exploring the conditions that mediate between the "new" social risks of contemporary long-term care provision and expectations for state intervention.

In the next section, I lay out a theoretical framework for tracing the construction of claims for alternative social arrangements to long-term care. I then elaborate the research design and methodologies used in this study. My analysis of grievance construction takes place in three parts. First, I analyze how individuals come to reinterpret longstanding care provision practices as harms or injustices requiring remediation. Second, I explore when and under what conditions participants shift responsibility for care dilemmas from the family to the market or state. Finally, I examine the claims that emerge from these processes of grievance construction, seeking to understand how participants formulate possible solutions to long-term care dilemmas, and why these solutions consistently fall short of "health security."

⁶ A growing literature considers the global consequences of the market for paid care when women from poor countries leave their own families to work as care providers in richer countries (Hondagneu-Sotelo 2001; Ehrenreich & Hochschild 2002; Hochschild 2003).

⁷ Researchers have linked caregiving stress to substantially increased rates of depression (Poulshock & Deimling 1984), physical health problems (Archbold 1982; Schulz & Beach 1999), and greater alcohol and psychotropic drug use (Alzheimer's Association & National Alliance for Caregiving 1999; George & Gwyther 1986).

⁸ Two notable federal exceptions include the Family and Medical Leave Act (FMLA) and the Dependent Care Tax Credit.

⁹ Medicare covers 100 days of care in a nursing facility for those recently discharged from a hospital and who need skilled nursing care or rehabilitative therapy, and it provides some home health benefits for those with chronic or disabling conditions who require skilled nursing care following hospitalization. Unlike many Medicaid programs, however, Medicare provides no assistance for those who need help with personal care (bathing, dressing, feeding, etc.), adult day care, or respite care.

Theoretical Frameworks for Analyzing Grievance Construction

Injustice Framing and Naming, Blaming, and Claiming

Social movement and sociolegal researchers have long sought to explain how it is that people overcome widespread resignation or quiescence during particular historical moments to challenge long-standing social conditions, practices, or modes of thought. For many years, the focus of these inquiries emphasized access to resources and political opportunities (Tarrow 1994; McCarthy & Zald 1977). Beginning in the 1980s, however, researchers observed that changes in material resources or political conditions become “opportunities” only when they are perceived as such by potential participants (D. Meyer 2004; Suh 2001; Kurzman 1996). Scholarly attention turned, therefore, to the role of political consciousness in grievance construction (Felstiner et al. 1980–81; Gamson 1992).

Social movement theorists have relied on the concept of *collective action frames* to understand the subjective work of redefining “as unjust and immoral what was previously seen as unfortunate but perhaps tolerable” (Snow & Benford 1992:173). Collective action frames refer to sets of beliefs and meanings that shape our understandings of our circumstances, including what kinds of action are imaginable, which targets are appropriate for blame, and what political concepts (such as rights) may be employed in a given context (see, e.g., Snow & Benford 1988; Steinberg 1999; Snow et al. 1986; Ferree et al. 2002). *Legitimizing frames* are interpretations that largely reflect and reinforce the status quo; they have a taken-for-granted quality, an inevitability or naturalness that leads to acceptance rather than critique of one’s circumstances (Gamson et al. 1982). By contrast, *injustice frames* are interpretations of experiences or conditions that support the conclusion that some moral principle has been violated and ought to be redressed.¹⁰ Social movement theorists generally view the adoption of injustice frames as a necessary—if insufficient—condition for political mobilization (Turner & Killian 1987; Moore 1978; McAdam 1982; Gamson 1992).

The sociolegal approach to studying grievance construction differs from the social movement approach in its emphasis on individual, rather than collective action. But it shares an understanding of the transformation of perceived injuries into legal

¹⁰ Gamson (1992, 1995; Gamson et al. 1982), who has perhaps most famously elaborated the concept of the injustice frame, observes that people do not necessarily choose between legitimating frames and injustice frames but may hold both to some degree, using these in different contexts to make sense of their circumstances and justify their actions or those of others.

claims as an interpretative process, shaped by a host of factors, including one's personal experiences with and knowledge about legal norms and rights, one's social position and ideology, and contact with third parties or other "agents of transformation" (see, e.g., Engel & Munger 2003; Felstiner et al. 1980–81; Greenhouse 1986; Nielsen 2000; Albiston 2005; Mather & Yngvesson 1981).

The two literatures have developed strikingly similar frameworks—referred to respectively as "injustice framing" (Gamson 1992) and "naming, blaming, and claiming" (Felstiner et al. 1980–81)—for analyzing the transformations in consciousness that occur in the construction of political and legal grievances. In what follows, I elaborate them as a single approach to studying the construction of grievances (see also Marshall 2003; Jones 2006).

The social movement framing and sociolegal literatures suggest that the first and arguably the most critical stage in grievance construction is the process of redefining—or "naming" (Felstiner et al. 1980–81)—as unjust or unfair those conditions or practices previously seen as acceptable or tolerable. In their seminal article on the emergence of disputes, Felstiner and colleagues observe that naming a problem—saying to oneself that a particular experience is in some way injurious—is perhaps *the* critical transformation: "Though hard to study empirically . . . the level and kind of disputing in a society may turn more on what is initially perceived as an injury than on any other decision" (1980–81:635). Gamson argues that to inspire mobilization for change, the evaluation of harm must be something more than a cognitive or intellectual judgment about what is equitable; rather, it must be a "hot cognition," "the kind of righteous anger that puts fire in the belly and iron in the soul" (1995:91). Naming an injury, then, requires attention to the emotional valence attached to an individual's perception that some standard or principle has been violated. Social movement scholars generally understand anger and indignation to be high activation emotions, motivating people to challenge the conditions that they perceive as injurious (Britt & Heise 2000; Jasper 1998). By contrast, emotions such as shame or guilt or embarrassment are considered low activation emotions, tending to paralyze rather than mobilize individuals to act (Taylor 2000). The quality or degree of emotions individuals attach to social conditions depends in part on what or who they perceive to be responsible for the injury (Ferree & Miller 1985).

Thus the second shift in political consciousness requires a target against which these emotions can be usefully vented—what Felstiner and colleagues (1980–81) refer to in their framework for grievance construction as "blaming." Gamson (1992) observes that while these targets can be anything from corporations or government agencies to individuals or groups, an injustice frame requires

some degree of concreteness in the target. To the extent that individuals see only impersonal or abstract forces as responsible for suffering—nature, society, God, “the system”—they are more likely to accept the status quo and make the best of it.¹¹ If reification and excessive abstraction act as impediments to grievance construction, so too can internalization of blame: people who blame themselves for a situation are less likely to see it as injurious (Britt & Heise 2000; Felstiner et al. 1980–81). Thus individuals must have a way of seeing the cause of their injury as the result of specific, identifiable forces external to themselves (Ferree & Miller 1985).

Finally, individuals must specify a remedy—or “claim”—some course of action to ameliorate the perceived harm (Felstiner et al. 1980–81; Gamson 1992). It is in the specification of claims that social movement and sociolegal researchers noticeably depart from their emphasis on political consciousness. Both literatures characterize claims as constructed separately from the interpretative processes of grievance construction; they focus on the conditions under which grievants will pursue externally defined remedies for their injuries, rather than on how individuals themselves conceptualize remedies as part of the grievance construction process. In the social movement framing literature, the analytical focus is on how social movements persuade potential participants to collectively mobilize for movement-defined solutions to social problems (see, e.g., Ferree 2003; Snow & Benford 1988; Snow et al. 1986). Similarly, in the sociolegal literature on disputing and legal mobilization, researchers typically assume the presence of legal remedies and focus their inquiries on the conditions that shape the willingness and capacity of people to pursue those remedies when they have experienced actionable injuries (see, e.g., Albiston 2005; Engel 1980; Engel & Munger 2003; Macaulay 1963; Marshall 2003; Gilliom 2001; Nielsen 2004). In both literatures, claiming is characterized as what individuals do as a result of the grievance construction process, rather than as part of the grievance construction process itself.

I argue, by contrast, that the conceptualization of claims is itself an important transformation in individual political consciousness. Grievance construction occurs in concrete social action as individuals evaluate and select from the ideational and institutional resources available to them for seeking solutions to problems in their everyday lives (see also Ewick & Silbey 1998; Mansbridge 2001). These resources include, but are not limited to, social movement collective action frames and existing legal remedies. They may also

¹¹ Gamson (1995) also warns of the opposite problem: by overly concretizing targets, there is a danger that people will miss the underlying structural conditions that produced the social condition at issue.

include public policies designed for other purposes or to benefit other constituencies, as well as market- or family-based solutions. Understanding how individuals select from among these available models to formulate solutions to their problems is critical to explaining how political support for (or opposition to) particular modes of redress emerge in response to new social problems.

Discursive Assimilation and the Construction of Claims

The starting point for this analysis is Polletta's (2000) work on "novel" rights claiming. Polletta sought to identify how civil rights activists developed "radical yet resonant" claims—rights claims that were not yet recognized in formal law, but which were effective in mobilizing people. She found that one of the primary ways in which activists developed resonant rights claims was by integrating rights discourse with more familiar ways of talking about and understanding the world. Civil rights activists, for example, often merged legal and religious idioms, combining arguments about citizenship and constitutional rights with principles of Christianity and spirituality. Polletta's findings are consistent with research conducted by Primus (1999), who argues that throughout American history, political elites seeking to offset the effects of war, poverty, or other adverse social conditions established—and legitimated—new rights by articulating principles that synthesized the new rights with previously existing understandings of rights (see also Sewell 1992).

Research on novel rights claiming offers an important insight into how resonant understandings of new rights claims are established: new claims must be discursively assimilated into previously existing ways of thinking and talking about the world. Notably, however, this research suffers from the same limitations as the broader social movement framing and sociolegal literatures: Polletta emphasizes the construction of claims by social movement elites in their attempts to mobilize participation in the civil rights movement, and Primus emphasizes the efforts of legislatures, courts, and political elites in legitimizing new understandings of rights. In both cases, grievants remain on the periphery of the analysis, depicted merely as an audience rather than as agents in the construction of new rights claims.

Claiming, I suggest here, involves shifts in political consciousness similar to those observed in the naming and blaming stages of grievance construction. Whether, for example, one chooses to call on the state to ameliorate unmet needs depends critically on how one also understands the responsibilities of the family and market for safeguarding social welfare. Similarly, how one conceptualizes the form of state intervention—e.g., as state entitlements or state

regulation of the market—depends on beliefs about the efficacy of market solutions and about what kinds of needs are substantively deserving of the privileged status that the “entitlements” label bestows. In other words, the process by which individuals imagine solutions to newly perceived injuries—the process of evaluating and selecting from a range of available models—is deeply imbricated with the assessments of family, market, and state responsibility that occur at earlier stages in grievance construction.

In the analysis that follows, I examine processes of grievance construction among individuals providing long-term care to family members with chronic diseases or disabilities, seeking to identify under what conditions the strains of long-term care provision form the basis for political claims for state intervention, and why these claims consistently minimize the role of the state in safeguarding health security.

Research Design and Methodology

Studying grievance construction is made difficult by the fact that it is a subjective process, requiring techniques for observing how individuals evaluate their experiences or conditions while minimizing reactivity to researcher suggestion (see Felstiner et al. 1980–81). To address this concern, this study employed a three-stage observational design: (1) nonparticipant-observation of support group meetings for individuals caring for adult family members with dementia, cancer, or similar chronic diseases; (2) peer group discussions involving the same caregiver support groups; and (3) one-on-one interviews with group participants.

Over a four-month period in 2004, I observed 68 meetings (one to two hours in length) of 14 different support groups for family caregivers in Los Angeles. The support groups provided a setting in which to observe how caregivers described—and sought solutions to—problems involving care provision as they arose in their everyday lives. Because race, ethnic, and class stratification in Los Angeles falls largely along geographic lines, I selected support groups located in most of the key “neighborhoods” of the greater metropolitan area.¹² This ensured a relatively diverse, if nonrandom, sample with respect to a variety of socioeconomic indicators. (For more information about the demographic makeup of the sample, see Appendix A.) To control for variability in caregiving experiences across diseases or disabilities, support groups were

¹² These included Santa Monica, West Los Angeles, Fairfax/West Hollywood, North Hollywood, downtown Los Angeles, East Los Angeles, the San Fernando Valley, Pasadena, and some surrounding suburbs.

limited to two specific classes of diseases: dementia and cancer.¹³ In total, 158 family caregivers participated in this stage of the study.

In the second phase of the study, I led nine of these support groups in peer group¹⁴ discussions about specific legislative initiatives involving long-term care. The purpose of the peer group meetings was to observe how participants related their personal caregiving experiences to larger sociopolitical issues of long-term care provision, and how they envisioned “solutions” to the dilemmas raised in providing long-term care. During each peer group session, I introduced four general policy proposals (pertaining to funding for respite care, caregiver allowances, tax credits for caregiving expenses, and paid family leave) and asked participants to discuss how the proposals would affect their personal situations and to consider the benefits and drawbacks of each proposal. Eighty support group members participated in this phase of the study. I then conducted one-on-one in-depth interviews with 66 support group participants to elicit more intensive discussions about their caregiving experiences, including their utilization (or nonutilization) of supportive services and benefits, their political backgrounds, and their views of state, market, and family responsibility for long-term care.¹⁵ Finally, to assess the effects of selecting participants based on support group participation, I also interviewed a smaller sample of 13 family caregivers who had *not* joined support groups.

This multimethod approach was designed to compensate for the limitations of each individual method with respect to the issues of researcher reactivity and control. Nonparticipant-observation provided a window into processes of grievance and meaning construction with minimal researcher reactivity. I played a passive role in observing the conversation of meetings, neither asking questions nor controlling the subject matter of the discussion. But to the extent that nonparticipant-observation minimized the effects of reactivity, it also minimized my control over the substance of

¹³ The burden of caregiving is well known to be greatest among those caring for patients with dementia (Dunham & Dietz 2003); the burden is exacerbated by the fact that the costs of supportive services for patients with dementia are rarely covered by Medicare or private health insurance policies and can be as much as three times greater than the costs of caring for people with other chronic diseases or disabilities. By contrast, the costs of caring for patients with cancer are more frequently covered by health insurance policies. The sample of cancer caregivers thus provided a useful comparative group for examining the extent to which costs of care provision influence the development of political consciousness.

¹⁴ Peer groups involve small groups of familiar acquaintances rather than strangers (as is more typical in traditional focus groups), and they play down the facilitator’s role in keeping the conversation going (Gamson 1992).

¹⁵ To identify any possible sequencing effects in this design, I reversed the order of the interviews and peer group session for one support group. No significant effects were observed.

participant conversations. One-on-one interviews provided a way to elicit more specific and focused information from respondents. Yet even the most carefully crafted questions run the risk of influencing respondent perceptions and responses. Peer groups are something of a middle ground, permitting observation of the interaction of participants and the interplay and modification of ideas (Albrecht et al. 1993), while also serving as a useful tool for observing the natural vocabulary with which participants construct meaning about specific issues posed to them.

To identify the conditions that give rise to political claims for state entitlements to long-term care, I conducted a comparative analysis of the needs, resources, and experiences of caregivers who relied exclusively on legitimating frames in talking about their care circumstances—reflecting the belief that families should care for their own, without the state’s intervention—and caregivers who relied at least in part on oppositional, or injustice frames—challenging norms about family caregiving as unfair. I coded field notes from support group observations and taped focus group conversations and interviews for instances of both kinds of frames using *Atlas.ti*, a qualitative analysis software program.¹⁶ Legitimizing frames included references to family “responsibility,” “duty,” and “obligation,” as well as expressions that naturalized the speaker’s circumstances or made them seem inevitable: “That’s life” or “That’s what families do.” For some speakers these were self-conscious statements: “I’m doing this because I’m the oldest daughter,” and for some they reflected taken-for-granted assumptions about care: “I’m taking care of Mom the way she took care of her own mother.” Injustice frames focused on explicit moral condemnations—“That’s unfair” or “That pisses me off.” Following Gamson (1992), the words themselves were not sufficient to qualify a segment of conversation as expressing moral indignation; the context also had to make the moral nature of the injustice claim clear. In addition, injustice frames could not be offset by other arguments; when participants qualified their statements by breaking the potential link between an unfairness claim and indignation—“It’s unfair, but . . .”—the text was not coded as injustice framing.

To analyze the relationship between chronic care needs and injustice framing, I also coded references made by caregivers to unmet care needs. These included instances in which caregivers sought assistance with care but encountered obstacles to successfully obtaining help. Obstacles ranged from lack of information

¹⁶ Note that because interviews offered the most complete analysis of the questions posed in this article, descriptive statistics refer only to the interview sample (79 participants) unless otherwise noted.

about where to find assistance, to concerns about affordability, service quality, and accessibility. Because I focus here on the construction of expectations for public provision, I emphasized only unmet care needs that could be redressed through public policy. There are also well-documented (see, e.g., Abel 1991; Brody 2004) emotional obstacles to obtaining formal care for a family member that are arguably more difficult to remedy through public policy, and these were not coded for analysis.

To analyze participants' views on the state's role in long-term care provision, I coded all references to state intervention. Definitions of "state intervention" and "government responsibility" in interviews and peer group discussions were deliberately left open to interpretation, as my intention was to discern not only whether respondents expected the state to intervene in the long-term care problems they faced, but also what form of state intervention respondents imagined or expected as a solution to their dilemmas. References to the state included: (1) state regulation of nursing homes, insurance plans, pharmaceutical companies, adult day care, home health care, and elder abuse; (2) state subsidies for market-based services, including subsidies to service providers such as home health care, adult day care, respite care, and nursing home care; tax credits for family care providers; and direct payments to family care providers; and (3) state provision of services, including state-run adult day care and nursing home care. In addition to the policy questions posed during peer group discussions, interview subjects were asked one targeted question about the state: "Do you think your experience as a caregiver for [family member] has changed the way you view the government's responsibilities for long-term care provision?"

Finally, to assess how caregivers understood the concept of "rights" or "entitlements" in the context of care provision, I analyzed the data for evidence of and variation in rights consciousness—how caregivers interpreted and used the language of law and rights in their everyday lives (see Ewick & Silbey 1998; Merry 1990). I coded all references to legal ideology, specific laws, government entitlements, and "rights talk." Interview subjects were also asked at the end of their personal interviews a targeted rights question: "If someone from another country were to ask you what rights family caregivers like yourself have in the United States, how would you answer that question?" Where appropriate, subjects were also given a follow-up probe: "What rights do you think caregivers *ought* to have in the United States?" These indicators of rights consciousness were analyzed with the data on legitimating and oppositional frames, unmet care needs, and state intervention to assess the conditions that shape caregivers' expectations for state entitlements to long-term care.

Injustice Framing Among Family Caregivers

The American welfare state is frequently portrayed as the “child of crisis” (Marmor et al. 1990). Normally self-reliant and independent, the American public has a long history of responding to (at least some) market or family “failures” by turning to the state for assistance. In this section, I more closely interrogate the relationship between social risks and expectations for state intervention by analyzing the conditions that mediate between contemporary long-term care needs and claims for state long-term care entitlements. I begin by elaborating the widely held view of long-term care provision as a family responsibility—what I refer to, following social movement framing theory, as a legitimating frame. I then compare the experiences of caregivers who relied exclusively on legitimating frames in talking about their care circumstances with those who relied on injustice frames, seeking to identify how individuals come to name long-standing care practices as harms or injustices requiring remediation, under what conditions they assign responsibility for remediation to institutions other than the family, and finally, how they construct solutions to the long-term care problems they encountered.

Legitimizing Frames

In a country where families provide 80 percent of long-term care (O’Brien & Elias 2004), it should come as no surprise that caregivers in this study uniformly demonstrated a tenacious commitment to the idea that it was their duty as family members to bear the primary burden of long-term care provision. The belief in family obligation is an archetypal example of a legitimating frame: the provision of care for a family member—no matter what the cost—was understood by most caregivers as the natural and normal thing to do. Indeed for many, the idea that anyone else—and in particular the government—should bear responsibility for either the costs or provision of care was simply inconceivable.

At the time of this study, Vincent¹⁷ was caring for his mother, who had been bedridden for five years following a stroke. Vincent worked full time and cared for his mother before and after work. A Vietnam vet, he joked that caregiving was the most difficult tour of duty he had ever had, but he did it, he insisted, out of a sense of obligation:

Because they brought me into the world, and my mom would do the same thing for me if I came back from overseas shot up or no legs or you know, something God forbid, that woulda happened.

¹⁷ All names of caregivers used in this article are pseudonyms.

But I felt I owed it to her. . . . That's what we were brought up with. From the time we were hatched, so to speak, that we were to take care of our older folks.

Asked why he had not hired any assistance, Vincent acknowledged that it was partly finances, but also a sense of obligation: "I think family would rather do it themselves. It's a matter of pride."

By conceptualizing their work as fulfilling a duty to their families, caregivers understood their situations as both natural and inevitable. Larry had given up his home to care for his parents, both of whom had been diagnosed with dementia. Complaining to his support group that his niece and nephew did not seem to share his values about caring for family, he opined, "Because it's an obligation that they have to do! So you sacrificed your life to move back with Mom and Dad? So you do it. You just do it. You just make the best of it."

When caregivers experienced frustration or exhaustion or resentment about their circumstances, the family responsibility frame served to mediate those emotions, often transforming them into feelings of guilt or embarrassment. Caregivers felt guilty for not doing enough or for wanting a break, and they felt embarrassed when they admitted they needed help. As one new participant confided to her dementia support group:

I'm not a good caretaker, because of my resentment and anger. I lose my patience. "Is today Tuesday?" "Yes, today is Tuesday." Then a minute later: "Is today Tuesday?" "Yes, today is Tuesday." And after a while I'm *screaming*! And you feel terrible. And you feel guilty. And you feel like you're not a good person.

By transforming high-activation emotions such as anger and resentment into low-activation emotions—resignation, shame, guilt—the family responsibility frame simultaneously legitimates and reinforces norms about family obligation for care provision.

It is important to emphasize that the family responsibility frame was resonant to some extent for *all* the family caregivers in this study, including those who also adopted more oppositional perspectives. But what is remarkable here is not the strength of the normative commitment to family responsibility, but the absence of a widely resonant oppositional frame. Caregivers whose feelings about their circumstances challenged or contradicted the expectations of family obligation struggled to find a language with which to articulate another view. Barbara's experience in this regard was typical. Caring for her husband had grave consequences for Barbara's emotional and physical health (she was suicidal at one point), her employment status (she was demoted), and her financial well-being (she spent all her savings and obtained a home equity line of

credit on her house to pay for supportive services). She said of all of this:

I think we're somehow brainwashed. There's something [about] the way we're brought up in this country. There's no empathy When my husband was first sick, and my family came up . . . my mother said are you having any fun yet? And it's like, do you think cleaning up poop and pee and taking care of a baby who's 50 years old is fun? . . . And I think somehow in this country, we're raised that it's your responsibility, you've got to do it. Don't complain and whimper . . . and then you're rewarded verbally. You know, if you do the job. Oh you're such a good person. Well, no I'm not! I don't like it!

The lack of a widely available discourse with which to challenge norms about family caregiving in the United States provides a useful opportunity to explore how, if at all, individuals come to challenge the widely held assumption that long-term care is exclusively the responsibility of family.

Injustice Framing: Naming the Harm or Injury

Most researchers agree that to (re)evaluate deeply entrenched beliefs, individuals require some *trigger*—an unexpected event or piece of information that causes them to think about their basic values and how the world diverges from them in some important way (Jasper 1998; Snow et al. 1998). President Clinton's health security plan assumed that unmet health care needs would serve as such a trigger, that the failure of the family or market to adequately provide health care would cause Americans to reallocate responsibility for health security to the state. In this study, the "naming" or recognition of unmet long-term care needs was indeed a necessary condition for re-evaluating norms about family provision of care, but it was not a sufficient condition for assigning responsibility for long-term care needs to the state.

Beliefs about family responsibility for care provision were not questioned—or even considered—by participants in this study unless or until they confronted some disparity between the care they felt obligated to provide their family members and their capacity—financially, emotionally, or physically—to satisfy that obligation. The "harm" or "injury" in the case of long-term care, in other words, is the belief that care provision is in some key respect falling short, that there are financial, physical, or emotional obstacles that caregivers on their own simply cannot overcome. In many cases involving chronic care, particularly for dementia, caregivers reached a point where they could not personally provide all the care they perceived to be required by the care receiver. Many worked outside the home on a full- or part-time basis; some had

child care responsibilities; some maintained separate households in other parts of the city, state, or country; some had health problems themselves; and most simply needed to attend to other parts of their lives. While a wide variety of market-based supportive services are available to help caregivers (including in-home skilled nursing or companion care, adult day care, respite care, and nursing home care), many caregivers do not know where to find these services,¹⁸ cannot afford the services they need,¹⁹ or face transportation or language barriers in accessing needed services.²⁰

Of the 79 caregivers in the interview sample, 47 (or 60 percent) described themselves as successfully meeting the perceived care needs of their family members. These caregivers included those whose family members needed relatively little assistance (typically because their conditions had not yet significantly deteriorated), those who had ample resources with which to find and/or purchase supportive services,²¹ those who had significant assistance in care provision from other family members, and those caregivers who obtained supportive services at low or no cost through California's means-tested Medicaid program. In all these cases, caregivers still faced the emotional and physical challenges of providing care to a family member with a chronic disease or disability, but they experienced no disparity between the care they felt was their duty to provide and their capacity to fill that obligation.

It is important to emphasize that there are strong cultural and psychological reasons for individuals to describe even the most challenging care situations as satisfactory. The perceived social stigma associated with being "bad" spouses or adult children if unable to provide all the necessary care for one's partner or parent, as well as the need to psychologically justify the often extraordinary sacrifices made for the sake of family, arguably encourage many people to either describe themselves—or to genuinely *see*

¹⁸ A 2003 survey of randomly selected California state residents who provide care to someone age 50 or over found that two-thirds of all caregivers who wanted education, training, or information about services did not know where to go to get those services (Scharlach et al. 2003). Similarly, three-quarters of caregivers needing financial or legal assistance on care-related issues did not know where to obtain it.

¹⁹ According to the MetLife Mature Market Institute, the average annual cost of a private room in a nursing home in the United States in 2004 was just over \$74,000; the hourly cost of home health care was on average \$19 per hour (MetLife Mature Market Institute 2005).

²⁰ Many caregivers also cited as an obstacle the opposition of their care receivers to receiving help or assistance from outside the family (see, e.g., Abel 1991; Brody 2004).

²¹ The capacity of caregivers to meet their perceived care needs was partly, but not exclusively, tied to income. Participants with reported incomes over \$50,000 were more than two and a half times more likely to say they could meet their care obligations. Because the sample is nonrandom, it is not possible to determine whether these differences are statistically significant, but the findings are consistent with the fact that market-based supportive services are expensive and available only to those with sufficient resources.

themselves—as successfully meeting the care obligations of their family members even in those instances where assistance may well be necessary.

Not surprisingly, caregivers who described themselves as successfully meeting the care needs of their family members were substantially less likely to characterize their care obligations as unfair or unjust. Of these 47 caregivers, 32 (or nearly 70 percent) relied exclusively on the family responsibility frame when talking about their care circumstances, reflecting the belief that families should bear the full cost and burden of care provision, without the state's intervention. By contrast, caregivers who struggled to satisfy their perceived care obligations were far more likely to re-evaluate taken-for-granted assumptions about family responsibility. As the following section elaborates, these perceptions of injury did not always lead to grievances, but without the perception of a divergence between expectations and reality—without the admission or realization of unmet care needs—grievance construction simply did not take place. Of the 79 caregivers in the interview sample, 32 (or 40 percent) mentioned unmet care needs. Of these, 26 (or more than 80 percent) relied on an injustice framing in describing their caregiving dilemmas.

Injustice Framing: Blaming

If unmet needs created an opportunity to re-evaluate deeply entrenched beliefs about family responsibility for care, how caregivers evaluated the discrepancy between their beliefs about family care provision and their capacity to provide that care depended critically on who they blamed for the divergence. To the extent that caregivers in this study internalized the blame for their predicaments, they were likely to feel shame, guilt, or embarrassment—low-activation emotions that are unlikely to lead to injustice framing (see Britt & Heise 2000; Taylor 2000). In these cases, beliefs about family responsibility again strongly influenced perceptions of personal responsibility for care problems. Some caregivers blamed themselves for not purchasing long-term care insurance when they had the opportunity. Others blamed themselves for not arranging their finances in ways that would legally qualify their care receiver for state Medicaid long-term care benefits. Most were just embarrassed that lack of income or poor health would stand in the way of meeting their care obligations to family. In all these cases, self-blame played a prominent role in defusing potential grievances. Belle, for example, had virtually no income at the time her husband was diagnosed with Parkinson's-related dementia, and for a time, she and her husband lived out of a warehouse they owned.

She could not afford in-home care for her husband yet could not qualify for Medicaid as long as she owned property.

Before we sold the building, our income was \$580 a month. And so that was not much. So our taxes went unpaid and all these things happened. . . . We had collateral, so we were not able to get support [from Medicaid]. We didn't have enough money for postage stamps, but they told us we could sell our properties and take care of it. But I guess that's true. We can't expect everybody else to pay our bill.

Similarly, caregivers who blamed impersonal or abstract targets for their frustrations—bad luck or “life”—were more likely to be resigned to the conditions in which they found themselves, with little sense of agency about or awareness of the structural conditions underlying their predicaments (see Gamson 1992). Heidi, who gave up her job and home to care for her mother, spoke of caregiving as a calling:

I gave up my life, you know? . . . And yes, I would like to go out there and do what I want to do, but you know . . . when that thing inside you says you have to do something, you cannot serve two masters. . . . [E]ither I put her someplace not so nice and say OK, me first. Or I do what my heart tells me to do regardless of what I missed out on. That's my choice. That's what I want to do. And sometimes . . . this is not what I *want* to do, but this is what I'm *called* to do.

High-activation emotions such as anger or moral indignation require an attribution of blame to specific, identifiable forces external to the potential grievants (Ferree & Miller 1985). Because care provision is so widely understood to be a family responsibility in the United States, the state was *not* a natural target for blame when most participants began caregiving. Indeed, many had never considered the role of the state (in any capacity) with regard to long-term care provision. Asked if participants thought their caregiving experiences had changed their attitude about the government's responsibilities for long-term care provision, the following responses were common:

I've never really thought of the government as being part of, you know, my world in that sense. (Susan)

I haven't much thought into that. I just feel like I'm responsible for my home life. (Louis)

That most caregivers wrestle with serious long-term care dilemmas without ever questioning the assumption that family should bear exclusive responsibility for care provision highlights the importance of expectations in injustice framing: we experience moral indignation only when our expectations for how we should be

treated have been violated. Joan, who for 18 years had been caring for her husband, participated in a peer group discussion about long-term care public policy. Silent for much of the discussion, she finally confided to the group that the idea of government responsibility for the costs of long-term care was new to her:

I think . . . that as a caregiver, we don't feel any entitlement. We never stamp our feet and say this is ridiculous, someone should be paying for this. . . . I mean, I just thought hey, it's the luck of the draw, isn't it? You know? . . . But if someone said, you know what? The government . . . I mean this whole discussion is like hey wow, that's another way to look at it, isn't it? Someone should be paying for this!

Joan's revelation to the group illustrates how the introduction of an alternative frame can create new expectations, or in Joan's words, a sense of entitlement. But where did caregivers derive these alternative views of long-term care responsibilities?

The social movement framing literature assumes that social movement organizations play a crucial role in shaping public conceptions about which targets are appropriate for blame for harmful or unjust social conditions. In the case of chronic care provision, however, most caregivers are unaware of advocacy organizations seeking long-term care public policy reform.²² There are a number of reasons for this. Because many care providers identify as husbands and wives, daughters or sons rather than as "caregivers," advocacy organizations have had great difficulty marketing themselves to their potential constituents (Levitsky 2006). In addition, because the American health care system lacks a formal structure for linking families (as opposed to individual patients) to public services and benefits, and because care provision can be an extremely socially isolating experience, the caregiving population remains an effectively invisible constituency, one that cannot be mobilized by traditional methods of organizational outreach. As a consequence, caregivers in this study rarely mentioned advocacy organizations in support group meetings or interviews, and when provided with a list of state and national advocacy organizations seeking policies to assist families in long-term care provision, respondents demonstrated extremely low levels of name recognition. While many knew of larger organizations like the AARP or the Alzheimer's Association, few caregivers in this study demonstrated any awareness of the specific collective action frames these organizations were promoting with regard to long-term care (Levitsky 2006).

²² For a more extensive analysis of the specific challenges of mobilizing families around the issue of long-term care reform and the role of advocacy organizations in the development of political consciousness among family caregivers, see Levitsky (2006).

While the social movement literature suggests that advocacy organizations would play a key role in providing individuals with blameworthy targets, the sociolegal literature on legal mobilization assumes that knowledge of and access to existing legal remedies or benefits shapes individual conceptions of blame. In this case, public policies did play a key role in shaping attributions of blame for caregiving problems, but not in the way sociolegal scholars would predict. There are few, if any, existing legal remedies or state entitlements available in the United States for families to “mobilize” in the conventional sense of enforcing rights or claiming benefits. But public policies designed for *other* purposes or to assist *other* beneficiaries constituted at least some of the ideational resources available to individuals constructing solutions to long-term care problems.

Caregivers were exposed to a wide range of alternative models of care provision during the course of caregiving, all of which served as potential paradigms for assigning responsibility for care struggles to institutions other than the family. In evaluating these alternatives, caregivers were primarily drawn to those models that assimilated their need for assistance with previously existing beliefs about the respective responsibilities of family, market, and state for care provision.

For a clear majority of grievants in this study, the most resonant model for assigning responsibility for care dilemmas to an institution other than the family was California’s means-tested Medicaid program (Medi-Cal). California’s Medi-Cal program offers relatively generous long-term care benefit packages for those who qualify for the program, including full prescription drug benefits and coverage for adult day care, in-home supportive services, and nursing home care. Because the income and asset eligibility levels are so stringent, very few caregivers in this study actually qualified for state assistance. But, notably, many participants knew of somebody who did qualify for Medi-Cal. Stories about Medi-Cal benefits circulated within support groups and friendship and neighbor networks, not only providing concrete examples of what the state *could* provide in the way of long-term care assistance, but also creating an expectation that certain types of services *ought* to be subsidized by the government and available to a wider segment of the American population. It was typically in conversations about Medi-Cal that caregivers most clearly articulated an injustice framing.

Susanna was caring for her parents, both of whom suffer from some dementia, her mother quite seriously. Despite working full time, she could only afford to hire a caregiver to stay with her parents for four to six hours a day. Her parents were unable to qualify for Medi-Cal benefits, as their pensions placed them just

above the eligibility cutoff line. Susanna observed, angrily, in her interview:

I have girlfriends at work say oh, just call up so-and-so, they can help you. [They'll say] my mother has 24-hour care. . . . [But] they don't pay a penny because they get on welfare . . . you have to be poor all your life or whatever, not work. And then when you're older, you get all the benefits, and that's just not fair! I think that's very unfair. My parents both have worked all their lives, and Daddy had two jobs for 16 years. And now he can't qualify because supposedly they make too much money.

For many participants, the need for assistance with care provision transformed the way they viewed the responsibilities of both family and state for the costs of care provision. Kathrina captured this shift in political consciousness in a story about her friend's mother, who suffered from severe diabetes and received benefits through Medi-Cal. In her friend's family, the youngest son lived at home, and due to their low income, he qualified for payments from the state under California's In-Home Supportive Service program as his mother's caregiver. "The son was getting paid by the state to take care of the mom. And I thought, you know, why are they paying you to take care of your parent? It's ridiculous! The kids should chip in and you should pull together and all this rah rah stuff." But Kathrina noted that once her stepfather was diagnosed with Alzheimer's, her perception changed dramatically. "When it hit *me*, I thought, oh my God! *Where's the help?* [laughs] I don't know, and I'm thinking you know I pay so much damn taxes! . . . I know I pay for the roads and all this stuff that I use, but where's the help back? Yes, it's changed my thinking a lot."

If the need for assistance with the costs or provision of long-term care changed the way many participants viewed the responsibility of the state, it was notable that Medicaid proved to be a more resonant model for state provision than Medicare. In many ways, Medicare would seem to be the more likely model for assigning responsibility for chronic care dilemmas to the state: not only are social insurance programs generally more respected than means-tested, "welfare" programs such as Medicaid (Cook & Barrett 1992), but most participants or their family members actually qualified for and received Medicare benefits for acute health care. It seems plausible, then, that caregivers would make the argument that if Medicare pays for the costs of acute care, it should also do so for costs associated with chronic diseases such as Alzheimer's or Parkinson's. But remarkably, *no* caregivers in this sample referenced Medicare as a source for their injustice frames.

I suggest that one reason the Medicaid model of social provision resonated more with caregivers than the Medicare model is

that Medicaid more closely accords with American cultural beliefs about family responsibility for care provision. In the United States, Medicaid and Medicare represent two distinct approaches to social welfare provision. Medicare is based on a social insurance model in which the state takes primary responsibility for meeting certain social welfare needs (retirement income, for example, or acute health care for senior citizens); Medicaid is based on a residualist or need-based model, in which families or individuals take primary responsibility for meeting social welfare needs, and the state steps in only when their most basic needs are not being met. Of these two forms of state provision, the underlying logic of Medicaid benefits arguably resonated with caregivers because it provided them with a way of bridging their normative commitments to family with their need for government assistance. Participants who assigned responsibility for long-term care dilemmas to the state believed, in other words, that the state had a role in helping families with care responsibilities, but only when traditional systems of family provision broke down.

The importance of finding a model for care assistance that modified but closely accorded with participants' pre-existing beliefs about long-term care provision can also be seen in the failure of international systems of public provision to serve as resonant models for assigning responsibility for unmet care needs. Most European countries, as well as Australia, Japan, and Canada, offer a wide range of government benefits for family care providers, ranging from free or subsidized home care, adult day care, and institutionalized care to tax credits and direct payment allowances for caregivers (Daly 2001; Daly & Rake 2003). But when participants in support groups and focus groups made references to how other countries approach the issue of long-term care, they were typically met with comments about the limitations of the health care systems in other countries and the problems faced by citizens who live there:

Well we know that those socialized countries or some of them, they have a very very high tax rate, much higher than we have. So that's something to look at too, paying for it. (Doris)

I had a coach down at the University of Arizona, his wife had a heart attack over in Hungary. . . . [He] said those hospitals over there in some of those countries, you wouldn't go in there if you were dying. (Tony)

In general, participants understood the health care systems of other countries to be so different from health care provision in the United States that international comparisons ultimately failed to resonate as a meaningful source of oppositional understandings of long-term care. Of the 41 interview participants who articulated an

injustice frame in this study, only three relied on international comparisons to do so (see Table 1).

Those participants who relied on sources of injustice frames other than Medi-Cal similarly emphasized models that closely tracked their pre-existing beliefs about care responsibilities. Five interview participants, for example, drew on their experiences with insurance companies in articulating an injustice frame. These caregivers—most typically caregivers for cancer patients—reported constant struggles to obtain coverage for various treatments and services and an ongoing fear that their insurance companies would drop their care receiver at their slightest misstep. In these cases, caregivers argued that if the insurance market bears the risk of acute health care provision, it should also bear responsibility for long-term care provision. Daniella, for example, was caring for her mother, who had advanced Alzheimer's disease. Neither she nor her mother could afford to pay for assistance, but her mother's insurance company did not cover supportive services, and her mother did not qualify for Medi-Cal. "I feel [her insurance company] should give us a lot of help because that's where her insurance is with," Daniella observed. "It's a *disease*, it's *medical*, so why shouldn't they offer more?" In these cases, participants either assigned responsibility to the state for regulating the insurance industry—leaving intact their more fundamental assumption that the insurance market, rather than the state, should bear responsibility for the costs of health care—or they blamed the insurance companies directly.

Given the pervasiveness of the insurance market in acute health care provision, it was notable that no participants assigned responsibility for unmet care needs to long-term care insurance companies. Participants in this study widely disparaged the long-

Table 1. Source and Distribution of Injustice Frames ($n = 41$)

Source of Injustice Framing ^a	Number (%) of Grievants Drawing on Source as Primary Injustice Framing
Means-Tested Medicaid Program	22 (54%)
Social Insurance Programs	0 (0%)
International Comparisons	4 (10%)
Insurance Companies	5 (12%)
Political or Moral Principles Regarding Care as a Government or Social Responsibility	10 (24%)
Other ^b	1 (2%)

^aThe categories were nonexclusive, meaning that it was conceivable that an individual could cite more than one source of injustice framing. In fact, only one individual, a British citizen who was caring for her mother in Los Angeles, drew extensively on more than one source for her injustice framing—both Medicaid and the comparative case of long-term care in England.

^bOne caregiver articulated a sense of moral indignation about state civil liberty laws, which make it very difficult to institutionalize elders living in unsafe environments.

term care insurance market for being unaffordable, inaccessible to people with diagnosed chronic diseases, and unreliable in delivering benefits to those who had actually obtained policies. Few caregivers knew anyone who was significantly assisted by any form of insurance coverage. Of the nearly 180 caregivers in this study, only six reported using long-term care insurance to cover the costs of supportive services. In most cases, grievants in this study viewed long-term care insurance as an ineffective tool for addressing the kinds of care crises that they routinely confronted.

Finally, some caregivers based their injustice frames on political or moral beliefs about the government's (or society's) responsibility to ensure the health and economic security of its citizens. Ten caregivers who identified themselves as political liberals emphasized that these were beliefs they held prior to their caregiving experience, and they experienced little dissonance between their need for state assistance and their expectations of the state in protecting the social welfare of its citizens. "I think that's an important function of government," one such participant observed. "I think ancient cultures, ancient civilizations always took care of their old. . . . The way [the government doesn't] want to pay for this or pay for that, I think is appalling."

Caregivers were exposed to a variety of state- and market-based models for assigning responsibility for unmet care needs, but they were primarily drawn to those models that closely accorded with pre-existing beliefs about family, market, and state responsibility for care provision. As the next section elaborates, participants relied on a similar discursive logic in constructing solutions for their long-term care dilemmas.

Injustice Framing: Claiming

The final shift in political consciousness necessary for grievance construction is the prescription of a remedy, some course of action to redress the perceived injustice (Snow & Benford 1988). It is in the specification of a remedy that we most clearly see how new claims for public provision are forged within, rather than independently of, processes of grievance construction. It is also in the specification of solutions to care dilemmas that we see why these claims seem to call for a substantially expanded state role but consistently fall short of calls for "health security."

Caregivers' claims for public provision in this study closely tracked the specific care needs giving rise to their grievances. Those caregivers who struggled to afford day care for their care receivers argued for subsidized day care (or, less commonly, state-run day care centers). Those who needed help inside the home argued for subsidized home health care. Those who complained

about the fragmentation of health services insisted that the state should create centralized, accessible “caregiver centers,” or that it should fund more social workers to assist caregivers. While the form of state intervention varied significantly, virtually all of the claims that emerged from processes of grievance construction reflected a substantially expanded view of the state’s responsibility for long-term care provision. But how did grievants justify the expanded state role they imagined? Were these claims, in other words, just another variation of the public ambivalence observed when President Clinton proposed his health security plan—supporting an increased state role, but reluctant to endorse a view of health care as a permanent commitment by the state to ensure that all Americans have access to adequate health care? Did grievants see their claims for state intervention as claims for new rights or entitlements?

To answer these questions, I compared the interpretative frameworks used by respondents to talk about their care circumstances with evidence of rights consciousness among the same participants. The data suggest a striking correspondence: participants who relied exclusively on legitimating frames for understanding their care dilemmas rarely understood their care needs as the basis for claims to rights or entitlements. By contrast, most caregivers who relied on injustice frames for understanding their caregiving dilemmas understood the concept of “rights” more broadly to include aspects of long-term care provision.

Caregivers in this study generally articulated four understandings of rights in the context of long-term care. First, some understood “rights” to be limited only to certain kinds of civil and political rights. These caregivers could not understand how to extend the rights frame in a meaningful way to the context of care provision. This was most clearly seen in responses to the targeted rights question,²³ where the most common response was one of befuddled incomprehension. Unlike those caregivers who requested some clarification of the question (e.g., “Do you mean paid caregivers or unpaid caregivers?”), these respondents fundamentally did not understand how to apply the concept of rights to their circumstances. The following responses are typical in this regard:

My goodness! [laughs] What rights do family caregivers have? My God. You got me. What *rights*? (Bridget)

What rights? [long pause] I don’t know about rights. To me, you just do what you have to do. (Alex)

²³ “If someone from another country were to ask you what rights family caregivers like yourself have in the United States, how would you answer that question?”

For these caregivers, the presumption that families should bear the primary burden of care provision was so taken for granted that the possibility of state obligations for care as a matter of *right* had never occurred to them. Their discomfort with the appropriation of the term in the context of care provision was evident in the following type of response:

I never thought of a right for a caregiver. And yet I hear it all the time. Rights for this and rights for that. I wasn't in that generation. I'm way back where you fended for yourself, I think. . . . Never thought of it that way. . . . Oh shoot. What right do you have to want a right? [laughs] What kind of answer is that? I can't answer it! (Belle)

A second interpretation of "rights" referred to established legal rights associated with elder abuse, power of attorney, conservatorships, and decisionmaking in the end stages of the care receiver's life. "Once you get the legal controls," observed one typical respondent, "like the durable power of attorney for financial and medical affairs, I would think that you have a lot of rights."

A third interpretation of "rights" included the "right to give care." Unlike those respondents who made reference to specific legal rights available to them through, for example, power of attorney, these caregivers referenced a moral right to advocate on behalf of their care receivers:

I can decide what I want to happen to [my husband]. . . . They can't come and tell me what to do with him! I can decide. My family and I can decide. So I think I have every right to do whatever I want. . . . I don't think no one can come and tell us anything. I think we have that right here. (Gabriela)

I would say that you have the right to get optimum help for the person that you're caring for. You have that right. It's a right. (Consuelo)

A final interpretation of "rights" emphasized social rights or entitlements, state-funded benefits and services such as financial support for caregivers, subsidized day care, respite care, etc. Whereas caregivers who understood rights to refer to formal or informal decisionmaking powers in care provision tended to understand themselves as having "as many rights as any other person has rights," caregivers who understood rights to include social provision observed that caregivers in the United States have *no* rights.²⁴ "I don't know that they have any rights," observed a typical caregiver in this regard. "I don't think caregivers are really addressed

²⁴ Remarkably, only two caregivers in this study referenced entitlements under the new California paid family leave policy, which had gone into effect just months before the observation period for this study began.

in our system.” When given a follow-up probe—“What rights do you think caregivers *ought* to have in the United States?”—these participants gave answers consistent with the “claims” they had articulated for their caregiving dilemmas: financial support, subsidized day care, respite care, and home care.

The distribution of these four understandings of rights corresponded to participants’ use of legitimating versus injustice frames. Three-quarters of those caregivers who relied exclusively on a legitimating frame in talking about their care situations (23 participants) interpreted “rights” narrowly, as legal or moral rights to give care—or they did not understand how to connect rights to care provision at all. By contrast, more than three-quarters of the caregivers who relied on an injustice frame during the course of the study (27 participants) described “rights” more expansively, to include rights to government entitlements.

For these latter caregivers, the processes of “naming” and assigning responsibility for unmet care needs produced “solutions” to long-term care dilemmas that challenged traditional demarcations between family and state responsibility for care provision. With the exception of those who identified themselves as political liberals and who held strong views of the state’s responsibility for health care prior to caregiving, most of the grievants in this study had given little thought to the state when they first began caregiving. That they now envisioned their care needs as the basis of claims to new rights or entitlements—despite a strong cultural bias against extending the concept of rights to contexts involving care and dependency (Gordon 1994; Fraser 1989)—suggests a significant transformation in how they evaluated the need for, and importance of public provision in solving problems regarding long-term care.

And yet, notably, grievants’ claims for public long-term care provision bore the imprint of the grievance construction process in which they were forged: rather than conceptualizing these rights as entitlements based on market participation or citizenship—as the notion of “health security” implies—grievants in this case justified these entitlements on the basis of *need*. Where grievants were drawn to need-based models of public provision as a way of assigning responsibility to the state for unmet care needs, they also relied on the discourse of need in articulating *claims* for public provision (see also Gilliom 2001):

[I]f you need the help, the financial help . . . you should be able to get it . . . I think just like with children, the government will give you a subsidy for low income families. And I don’t know how you would determine who would [be eligible]. I don’t think that’s your question, just there is a need. (Gladys)

The homemaker service they have now, is only for low income. It should be extended to anyone and everyone who needs that money. (Dori)

This understanding of public long-term care provision as being based on need rather than citizenship (or market participation) accords closely with the discursive logic participants used in the attribution of blame: to conceptualize long-term care needs as justifying new state entitlements, participants required a way of integrating their need for state assistance with deeply held beliefs about family responsibility for care provision. The social insurance model of public provision in most cases failed to provide such a framework, instead symbolically suggesting to many caregivers that the state would be “taking over” long-term care obligations that more properly belonged to the family. Ruth, a caregiver for both her parents, captures this concern that relying on the state for more than need-based benefits might be perceived as abandoning one’s responsibilities to family:

I have mixed feelings about it. . . . I’m definitely believing in home support services, definitely believe people need to have assistance with respite care and caregiving. . . . So I’m much more for the government helping people out with these things. But I also can’t say that I totally believe that I don’t have any responsibility in this. So . . . I think what I would like for people to do, for government to do, is to help people when they need help.

A need-based model of state provision, characterizing care provision as primarily a family responsibility and providing government “help” or “assistance” only when families need it, presented caregivers with a way of accepting state intervention, without in any way diminishing their commitments to family.

Two caveats are worth mentioning here. First, in arguing that a need-based model of social provision was more resonant than a social insurance model, I do not mean to suggest that caregivers were opposed to the idea of extending Medicare benefits to include long-term care provision. Few caregivers in this study ever demonstrated outright opposition to any form of government assistance. Rather, I seek to explain why participants’ claims for public long-term care provision seemed to call for an expanded state role without recourse to the entitlements-based discourse associated with the country’s most popular welfare state programs. In this case, even those caregivers who challenged norms about family responsibility for care nevertheless retained the cultural assumption that care provision is a responsibility of families first, insisting that the government should assist families only when all “private” systems failed.

Second, in arguing that a need-based model of social provision was more resonant than a social insurance model, I am also not

suggesting that caregivers were in any way content with the current system of Medicaid-administered long-term care benefits. On the contrary, participants' perceptions of injustice were due largely to their inability to obtain Medicaid benefits under the current system: most participants in this study were middle- or working-class caregivers whose family members were not eligible for Medicaid benefits under the program's strict means test. Thus while participants believed that the government should assist families with care provision only when they cannot meet their basic needs, they nevertheless held an expansive definition of "need," one that envisioned not just the poor, but the middle class, as appropriate beneficiaries of public provision.

Conclusion

The American welfare state rests upon a conception of the state as the "ultimate risk manager" (Moss 2004), reallocating and reducing certain social risks through social insurance programs and other state guarantees against the uncertainties and hazards of a modern capitalist society. The reluctance of the American public to reallocate the risks of long-term care provision—even in the face of well-documented unmet needs—suggests that the relationship between unmet health care needs and political claims for state entitlements is more complex than conventional accounts allow. I have suggested that to understand American ambivalence toward state entitlements to health care, we need to understand more precisely how unmet health care needs shape the constellation of norms and beliefs that individuals hold about family, market, and state responsibility for social welfare. This article has sought to extend current models of grievance construction by shifting the analytical focus away from the mobilization of existing remedies, to instead consider the construction of remedies or solutions as a key transformative stage in the development of political consciousness. In constructing solutions to new or newly perceived social problems, individuals evaluate and select from a range of available institutional and ideational resources. While these resources may include collective action frames and existing rights and benefits, individuals often confront social problems that have not yet been addressed by social movements, legislatures, or judges. Understanding how individuals faced with new social risks navigate between traditional conceptions and new realities of everyday life is critical to identifying what solutions will resonate with the public as legitimate and appropriate political remedies to contemporary social welfare problems.

In the case of long-term care, virtually all the caregivers in this study maintained strong normative commitments to the idea that families should bear primary responsibility for long-term care on their own. So widespread was this presumption of care as a family responsibility that the possibility of any alternative interpretation did not occur to most caregivers until or unless they faced some crisis in care. *How* participants evaluated their care crises—whether they saw unmet care needs as a source of guilt or embarrassment or anger and moral indignation—depended largely on who they blamed for their unmet care obligations. For most caregivers, the government was not a natural target for blame; few had any specific ideas when they began caregiving about what the government could or ought to do to assist in long-term care provision. The experience of caregiving, however, in most cases exposed caregivers to a wide variety of alternative models for care provision, ranging from Medicare to systems of social welfare provision found in other countries. The most resonant model for assigning responsibility for the costs or provision of long-term care to an institution other than the family was California's Medicaid program, which provides long-term care benefits and services to the state's poorest residents. I have suggested that California's Medicaid program was a resonant model for so many participants—despite the fact that most did not actually qualify for benefits and despite the stigma associated with “welfare” programs—because it provided a model of public provision that bridged participants' need for state assistance with deeply held beliefs about family responsibility for care.

The political claims, or proposed solutions, that caregivers constructed for their care dilemmas were similarly forged in this process I refer to as discursive assimilation—a way of integrating new needs for state assistance with more familiar ways of talking and thinking about social welfare. Discursive assimilation produces claims that challenge existing social arrangements for long-term care but do so without substantially altering underlying beliefs about the respective responsibilities of family, market, and state for the costs and provision of chronic care. Thus on the one hand, grievants' claims in this case represented an expanded view of the state's responsibility for social welfare provision, as well as what kinds of needs ought to be protected as “rights” or “entitlements” by the American welfare state. By calling on the state to ameliorate care dilemmas long considered private, family affairs, grievants demonstrated a substantive shift in their beliefs about the role of the state in matters involving care or dependency.

But on the other hand, grievants' claims for state intervention were articulated within a residualist welfare state framework that conceives of only a minimal role for the state in safeguarding social

welfare. If, as Polletta argues (2000), “radical but resonant” meanings of rights can be constructed by integrating rights discourse with other normative languages, here we see that integration significantly tempers how “radical” new rights claims prove to be. If this residualist ideology of the state had *not* played such a substantial role in attenuating grievants’ claims for public provision, if instead participants were constructing grievances in a culture with a stronger tradition of social protectionism, we might have observed claims for public provision that called for new ways of conceptualizing citizenship and the social responsibilities of care. Instead, caregivers’ claims called for something substantially less: to ensure that their most basic needs are met by family, with help when absolutely necessary from the state.

The policy solutions conceptualized by participants in this case may fall well short of conventional expectations for social rights or entitlements as a response to new social risks, but their implications for future public policy reform should not be underestimated. The claims for public provision articulated in this study suggest an emerging consensus among individuals with unmet long-term care needs for a form of social welfare policy that diverges significantly from the agendas of both political conservatives and liberals.

With regard to reform efforts on the political right, participants’ calls for expanded long-term care benefits for the middle class represent a striking rebuttal to those who seek to limit the state’s role in social welfare provision to that of a safety net only for the very poor. Because Medicaid is the only public program to offer substantial assistance with the costs of long-term care, the means-tested program has been used more frequently in recent decades by middle-class families with substantial chronic care needs who have no choice but to spend down their assets in order to qualify their care receiver for state assistance for nursing home care.²⁵ Concerns among fiscal conservatives that Medicaid is evolving into a “middle-class entitlement” (Burwell 1991; Moses 1996) have resulted in a wide range of legislative initiatives designed to make it more difficult for the non-poor to use Medicaid as a safety net.²⁶ The findings from this study suggest that not only is it true that

²⁵ In 2000, approximately 40 percent of nursing home residents relied on Medicaid as their primary source of payment at admission (either because they were already poor or because they had previously spent down their assets due to high medical expenses) (O’Brien & Elias 2004). Another 20 percent entered nursing homes and subsequently depleted their life savings until they were technically impoverished—at which point they qualified for Medicaid coverage.

²⁶ These initiatives have included restrictions on asset transfers, penalties for attempts to illegally shift assets for the purpose of gaining Medicaid eligibility, and controversial estate recovery programs to recoup assets after the death of middle-class homeowners who receive Medicaid benefits (Grogan & Patashnik 2003).

public expectations *are* evolving toward a “middle-class entitlement,” but, paradoxically, the means-tested benefits provided under the public assistance program are serving as the very foundation for these expectations.

Participants’ claims for state intervention are equally at odds with the agenda of those on the political left who seek a social insurance solution to the problem of long-term care: the allure of the *need*-based model of public provision among the mostly non-poor participants in this case defies the conventional wisdom that middle-class support will necessarily gravitate toward universal entitlement programs rather than means-tested programs (Skocpol 1991). This is not to say that Medicaid itself should—or could—serve as a programmatic solution to the long-term care problems of the middle class. Medicaid was never intended to be the primary source of public funding for long-term care assistance, and the public perception of Medicaid services as inferior to services provided under private payment plans suggests that expanding the Medicaid program to the middle class would not be a politically viable solution. But the findings from this study emphasize the important point that regardless of how difficult long-term care provision has become for contemporary American families, and no matter how striking the presence of unmet health care needs, Americans retain the belief that families should bear primary responsibility for long-term care and remain uncomfortable with the idea of fully reallocating the risks of chronic care to the state.

If the claims articulated by grievants in this case depart from the reform agendas of both the political left and right, so too do they diverge from existing social welfare programs. The American welfare state is well known for its two-tiered programmatic framework: structural distinctions between contributory, social insurance programs and noncontributory public assistance programs are accompanied by well-documented cultural demarcations between “deserving” citizens and “undeserving” charity recipients, and between rights-bearing beneficiaries and dependent clients (Skocpol 1988; Gordon 1994; Fraser 1989). The findings from this study suggest, however, that those struggling with the consequences of the unfolding crisis in long-term care envision solutions to their unmet care needs that bridge both tiers of the American welfare state. Grievants relied on a model of means-tested social provision that emphasizes family responsibility, yet they sought long-term care security for a broad swath of the middle class; they justified their claims on the basis of need, yet understood their claims as the basis for *rights* and a commitment by the state to safeguard their health and welfare.

Finally, it is important to emphasize again that caregivers' "solutions" in this case were constructed largely independent of the influence of social reform organizations. While I address the role of advocacy organizations more fully elsewhere (Levitsky 2006), it is worth considering here how advocacy organizations would influence the construction of grievances if they were better able to reach their isolated constituencies. Would advocacy organizations have helped caregivers in this case to construct political solutions that more fundamentally challenged the paradigm of family provision of care? Interviews with activists from state and national advocacy organizations pursuing long-term care public policy reform suggest that advocacy organizations in the current political context are actually proffering more conservative policy alternatives than caregivers themselves imagine on their own. Advocacy organizations seeking to influence public policy do not construct collective action frames in a political vacuum but are themselves influenced by political institutions, power relations, and the terms of dominant political discourse (Ferree 2003; Steinberg 1999). Activists seeking long-term care public policy reform today confront economic and ideological concerns about *existing* systems of social provision that sharply constrain the range of policy solutions they can credibly seek for "new" social problems such as long-term care provision. As a consequence, most advocacy organizations, including the AARP and the Alzheimer's Association, are currently pursuing modest, incremental, market-based reforms²⁷ that bear little resemblance to the needs or expectations of caregivers for an expanded safety net for the middle class. The irony is that just as advocacy organizations could potentially transform the ways individuals view the responsibilities of family, market, and state for safeguarding social welfare, so too could this growing constituency transform the politics of social provision by mobilizing for the political solutions that they imagine.

By analyzing how individuals navigate between the new social risks of contemporary care provision and long-standing beliefs about the responsibilities of family, market, and state, we obtain a much more nuanced view of the relationship between unmet needs and political demand for an interventionist state. Understanding that relationship, I have argued, should be an imperative for social movement and sociolegal scholars studying the construction of grievances and the dynamics of social change.

²⁷ Most market-based policy reform proposals primarily focus on making long-term care insurance more available to the middle class by offering tax credits for individuals purchasing insurance policies.

Appendix A: Demographic Statistics for Family Caregiver Sample ($n = 176$)

Table A1

	Support Group Participants ($n = 158$)	Peer Group Participants ($n = 80$)	Interview Subjects ($n = 79$)
Sex of Caregiver	$n = 158$	$n = 80$	$n = 79$
Female	104 (66%)	54 (67%)	57 (72%)
Male	54 (34%)	26 (33%)	22 (28%)
Race/Ethnicity	$n = 156$	$n = 80$	$n = 79$
Black	24 (15%)	12 (15%)	17 (22%)
Hispanic	27 (17%)	18 (23%)	9 (11%)
Asian/Pacific Islander	4 (3%)	4 (5%)	4 (5%)
Caucasian	100 (64%)	46 (57%)	48 (61%)
Other	1 (1%)	0 (0%)	1 (1%)
Relationship to Care Receiver	$n = 158$	$n = 80$	$n = 79$
Spouse or Partner	94 (60%)	47 (59%)	39 (49%)
Son or Daughter	52 (33%)	25 (31%)	36 (46%)
Other	12 (8%)	8 (10%)	4 (5%)
Median Age			$n = 78$ 63
Income			$n = 75$
<\$30,000			18 (24%)
\$31–50,000			17 (23%)
\$51–70,000			11 (15%)
over \$70,000			29 (39%)
Political Ideology			$n = 75$
Liberal			33 (44%)
Moderate			21 (28%)
Conservative			9 (12%)
Other			12 (16%)
Party Usually Votes for			$n = 75$
Democrat			54 (72%)
Republican			12 (16%)
Other			9 (12%)

*Membership in the three groups was partially, but not entirely, overlapping. Peer group and most interview participants were recruited from support groups. In all, 50 individuals participated in all three groups.

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